



Goodhead, A., Speck, P., & Selman, L. E. (2016). 'I think you just learnt as you went along' – community clergy's experiences of and attitudes towards caring for dying people: A pilot study. *Journal of Palliative Medicine*, 30(7), 674-683.
<https://doi.org/10.1177/0269216315625860>

Peer reviewed version

Link to published version (if available):
[10.1177/0269216315625860](https://doi.org/10.1177/0269216315625860)

[Link to publication record in Explore Bristol Research](#)
PDF-document

This is the author accepted manuscript (AAM). The final published version (version of record) is available online via Sage at <http://pmj.sagepub.com/content/30/7/674>. Please refer to any applicable terms of use of the publisher.

University of Bristol - Explore Bristol Research

General rights

This document is made available in accordance with publisher policies. Please cite only the published version using the reference above. Full terms of use are available:
<http://www.bristol.ac.uk/red/research-policy/pure/user-guides/ebr-terms/>

'I think you just learnt as you went along' – Community clergy's experiences of and attitudes towards caring for dying people; a pilot study

Authors:

Andrew Goodhead. MA., PhD., MSc.^a (Corresponding author)

Peter Speck BSc., BA., MA., DM.^b

Lucy Selman. BA., MPhil., PhD.^b

^a *St Christopher's Hospice, Sydenham. London. UK.*

^b *Cicely Saunders International, King's College London. UK*

Corresponding Authors Address: St Christopher's Hospice, 51-59 Lawrie Park Road, Sydenham. London. SE26 6DZ. UK.

Email: a.goodhead@stchristophers.org.uk

Telephone: +44 (0)20 8768 4604

Word count: 3231

Keywords

Clergy; palliative care; dying; death; pastoral care; education and training; spiritual care; hospice; palliative care unit; chaplaincy

Abstract

Background: Spiritual distress is a factor associated with poor outcomes at the end of life. Timely interventions, assessing and meeting spiritual distress among patients is contained within nationally agreed guidance. Community clergy are well placed to work alongside healthcare professionals and chaplains to meet spiritual needs.

Methods: Qualitative interviews among Christian clergy in two South East London boroughs and a self-completed Death Anxiety Questionnaire.

Results: 14 clergy were interviewed from 6 Christian denominations. Participants described their experiences of ordination training and how helpful

this had been for their work among Christian communities. Respondents were invited to discuss their knowledge of, and involvement with palliative care services. Each interviewee also accounted for their understanding of pastoral care and spiritual care and considered whether any differences existed between these terms, and if so, what they were. Overall clergy lacked any detailed formal training and had little experience of working with, or relating to palliative care providers. Recommendations are made to improve educational opportunities and working relationships.

Conclusions: Creating opportunities for clergy and palliative care staff to meet and undertake shared training will enhance the quality and level of care for people dying at home who wish to receive spiritual support. Enabling clergy to develop links with local palliative care centres will enhance confidence for both clergy and staff. (216 words)

What is already known about this topic?

- Spiritual distress is a factor in poor outcomes at the end of life
- Community based clergy would value education and training in issues around end of life care
- UK government policy has recognised the value of the voluntary sector in end of life care

What this paper adds?

- Creating opportunities for education in end of life care for community based clergy would enhance confidence in caring for dying people
- Better working relationships between community clergy and palliative care providers would improve care for those dying in community settings
- Community clergy should educate palliative care providers in the language of pastoral care and their role in care for dying people

***'I think you just learnt as you went along'* - Community clergy's experiences of and attitudes towards caring for dying people**

Background

Spiritual distress, including meaninglessness and hopelessness, is known to be highly prevalent in advanced disease and is associated with poor quality of life (1), end-of-life despair (2), requests for physician-assisted suicide (3), and dissatisfaction with care among patients (4).

Advanced disease may lead an individual to an awareness of impending death. A combination of physical, emotional, social and spiritual pain, in the model of 'Total Pain' described by Cicely Saunders challenges an individual to consider the nature of existence and unanswered questions may lead to demoralisation (5). Hopelessness and helplessness are caused by the loss of purpose and meaning in life which can lead to demoralisation. Intractable physical symptoms, isolation and spiritual issues contribute to a sense of personal demoralisation. (6) Kissane created a typology of existential distress which includes anxiety around death, loss and change, dignity, aloneness, meaning and mystery. (5) Although the typology is aimed at a deeper understanding for the doctor's holistic care of patients, the typology has implications for the engagement of chaplain's and community clergy.

The need to identify and respond to the spiritual needs of patients with incurable, progressive disease and their families is enshrined in palliative care policy guidance globally (7, 8, 9, 10). In the UK, the National Institute for Health and Care Excellence (NICE) and the National Health Service (NHS) recognise

the need for appropriate spiritual and religious support towards the end of life (11, 12), highlight the importance of discussing spiritual and religious issues in end of life conversations (13), and stress that spiritual support should be offered in the setting in which the patient resides (14). In conjunction with this, population ageing and evidence that the majority of patients would prefer to die at home rather than in hospital (15, 16, 17) mean that extending palliative care services into community settings is recognised as a priority in service development in Europe.

Partnerships between community clergy and healthcare professionals including chaplains could help to both meet patients' needs for spiritual support and facilitate the provision of palliative care at home. The NHS recognises the value of the voluntary sector in end of life care (18) and in particular the role that community clergy currently could play given the insufficient number of healthcare chaplains to meet every person's needs (11, 12, 14). An evidence-based 2010 report recommends a collaborative model of spiritual care in which health and social care professional's work with local faith leaders to meet patients' and families' needs (19). Partnerships could be established by inviting community based clergy into palliative care units or hospices and offering educational workshops and training on spiritual care at the end of life. Topics for study should include despair, hope and hopelessness and existential distress. This would enhance the pastoral and theological expertise of clergy. Placements for clergy in end of life care settings, addressing broadly spiritual and specific pastoral issues in a practice based, supportive environment would build confidence between end of life care providers and clergy. Healthcare

professionals, including chaplains could be invited to teach on pastoral care courses for clergy in training, or on chaplaincy courses. Additionally, it would assist healthcare professionals to be educated by community based clergy in the nature of their role.

While healthcare chaplains play a unique role in meeting the spiritual needs of the dying (20), including those of patients and families who are not religious (21), increasing demand on services and the diversity of Western societies in terms of culture and faith mean that clergy in the community could play a central role in ensuring patients' and families' needs for spiritual support are met (14).

However, the feasibility of this recommendation depends on the attitudes and skills of the clergy as well as of palliative care providers. At present, little is known regarding how clergy working in community settings relate to and care for dying people, whether from the clergy's own congregation, or referred to them by a palliative care provider. Evidence is also limited regarding the extent to which clergy are comfortable discussing concerns around dying and death, and whether they feel confident and competent in the provision of spiritual care. While clergy may be comfortable with the concept of pastoral care – described as being present with the dying and providing an opportunity for reconciliation, sustenance, guidance and growth (22) – pastoral care takes place within the context of a faith community rather than healthcare.

Within palliative care, spiritual care refers not only to religious support but to wider forms of care related to patients' and families' spirituality, 'the aspect of humanity that refers to the way individuals seek and express meaning and purpose and the way they experience their connectedness to the moment, to self, to others, to nature, and to the significant or sacred' (23). Spiritual care education is needed for all staff and volunteers to enable them to meet this aspect of a person's being. Clergy will naturally work primarily among their own religious group. However, community based clergy, willing to collaborate with palliative care services should receive education to understand spirituality as a concept and the ways in which spiritual issues can be addressed. This would develop their ability to support people at the end of life. It is unclear how well-prepared clergy are to provide care of this kind to people approaching death and their families. Two studies conducted in the USA suggest clergy have little formal education in end of life issues (24) and a lack of dialogue between health providers and clergy has been reported (25).

This study therefore aims to explore the experiences, attitudes and training in caring for the dying of clergy working in South London, UK, to inform the development of models of integrated spiritual care provision across community and palliative care settings and clergy training.

Methods

Design and setting

Qualitative methods were employed to explore, understand and describe the experiences of clergy in two South East London boroughs (Lambeth and

Southwark) via in-depth, face-to-face, semi-structured interviews. Interviews typically lasted between 60 and 90 minutes. Both boroughs are within the catchment area of a South London hospice service.

In 2001 Lambeth was populated by 33% ethnic minorities and 50% white British. The borough population stood at 272,000 in 2007. Just over 11% were aged over 60. Lambeth is the 5th most deprived London borough and the 19th most deprived UK borough (2007 figures). Over 130 languages are spoken in the borough (26). 1,355 deaths were registered in Lambeth in 2011 (27). In Southwark, the population of the borough in 2007 stood at 274,000, with 62% being white and 27% from Black and ethnic minorities. In 2007 11% of Southwark residents were of pensionable age (28) and the borough was the 9th most deprived London borough in 2007 and the 26th most deprived borough in England (29). 1,340 deaths were registered in Southwark in 2011 (30). These boroughs were selected as they are representative of the boroughs served by this South London Hospice Service.

Recruitment

Participants were identified using publicly available denominational directories of the Anglican, Methodist, Roman Catholic, Baptist, United Reformed Churches and the Salvation Army. Eligible participants were stipendiary clergy living or working in Lambeth or Southwark. Contact was by letter. Purposive sampling aimed to ensure that female clergy and clergy from Black and minority ethnic communities working in these denominations were included (31, 32).

The study was approved by King's College, London College Research Ethics Committee and written informed consent was obtained from each participant prior to interview.

Data collection

The semi-structured topic guide covered: training undertaken relating to care for the dying, academically and in placements; whether the training had been of help in caring for dying people; training post-ordination; knowledge of, and contact with, end of life care services; understanding of end of life care; definitions of pastoral and spiritual care; theological understanding of dying and death; personal and professional experiences of caring for dying people; and what further training or support would help now. One interview with each participant was conducted at a time and in a setting chosen by the participant, recorded and transcribed verbatim. A reflexive notebook was maintained throughout the study.

Prior to interview, all participants were sent a Death Anxiety Scale (Table 1) for completion and return (33), to assess their personal attitudes to death. The DAS was developed by Donald Templer as a means of understanding respondent's perspectives of issues about death and dying. Of the fifteen items in the scale, nine are 'true' and six 'false'. Each scores one point (33). A score of fifteen indicates a high death anxiety. This scale, developed in the late 1960's now appears anachronistic with the question 'I shudder when I hear people talking about a World War III'. Political changes and the rise of terrorism which has no geographical boundaries, has meant a World War III is less

prevalent in people's thinking except symbolically. The DAS was validated in America among two distinct groups; psychiatric patients in a mental hospital and college students. Scores range between 0-15, with 15 indicating greater death anxiety. To achieve a score of 15 requires answering nine items as 'true' and six as 'false' (Table 3).

Table 1

THE 15 DAS ITEMS

Content	scoring
I am very much afraid to die.	T
The thought of death seldom enters my mind.	F
It doesn't make me nervous when people talk about death.	F
I dread to think about having to have an operation.	T
I am not at all afraid to die.	F
I am not particularly afraid of getting cancer.	F
The thought of death never bothers me.	F
I am often distressed by the way time flies so very rapidly.	T
I fear dying a painful death.	T
The subject of life after death troubles me greatly.	T
I am really scared of having a heart attack.	T
I often think about how short life really is.	T
I shudder when I hear people talking about a World War III.	T
The sight of a dead body is horrifying to me.	T
I feel that the future holds nothing for me to fear.	F

Analysis

Transcribed interviews were imported into Nvivo 8 (34) for thematic data analysis (35). The first author worked with a coding frame, created by coding a sample of the transcripts; this was then reviewed by the Rev Dr Peter Speck for content and to ensure themes and sub-themes were mutually exclusive and semantically consistent. The agreed final version was then applied to all transcripts by the first author.

Data from the Death Anxiety Scale was tabulated by respondent and item and used to enhance the qualitative data analysis, e.g. by examining whether participants' behaviours, attitudes and experiences of caring for dying people were influenced by personal views around their own death.

Results

Sample characteristics

155 clergy were contacted. 14 clergy agreed to participate and were interviewed: one Salvationist, two United Reformed, two Baptists, three Anglican, three Roman Catholics and three Methodists (Table 2). The oldest participant was 68 years, and the youngest 29 years. The mean participant age was 52.5 years. The mean number of years in ministry was 21. Two participants were female and three male clergy were from Black and Minority ethnic communities.

The response rate was low at 9%. If an invitee had not responded within two weeks, a follow up letter was sent. Five Baptists declined the invitation to

participate. Among the reasons offered were retirement, a perceived lack of experience and a refusal to complete a Death Anxiety questionnaire. Three Methodists declined to take part, one because of a refusal to complete a questionnaire and two due to retirement. Three Salvationists declined to participate due to lack of experience, a refusal to complete a questionnaire and pressure of time. Among the Church of England clergy who declined to take part, one clergy member had died, two lived outside the boroughs of Lambeth or Southwark and one declined to complete the death anxiety questionnaire. Six Roman Catholics replied to the invitation declining to be included. Of these, one had died, one was non-stipendiary, one cited pressure of work and two declined to fill in a questionnaire.

Table 2: Participant characteristics

Denomination	Methodist	3
	United Reformed	2
	Church of England	3
	Roman Catholic	3
	Baptist	2
	Salvation Army	1
Gender	Male	12
	Female	2
Age	Mean age	52.5 years
	Range	29 years to 68 years
Borough	Southwark	8
	Lambeth	6
Ethnicity	White British	10
	White Irish	1
	African Caribbean	1
	African	1
	Pakistani	1
Years in Ministry	Mean period	21 years
	Range	6 months to 41 years

Findings

Participants were invited to describe their experience of training for the ordained ministry and specifically to discuss the amount and level of training received on caring for dying people. All participants had undertaken classroom-based training, ranging from two to eight years in duration, involving university-validated courses and in-house training, *'In terms of [University] it was really only the kind of deeper, the broader theological themes because it is an academic course. In terms of the in-house training, the [college] 'Life and Service' course covered ... areas of sort of practical caring in the parish, ministry, that sort of thing, so we would have a session on and discussions about caring for the dying'* **CE/76/f**. Pastoral care education was not perceived as a priority of training; *'because of the nature of the training I did which was mostly doing a university course I missed out on some of the training ... I generally kind of remember in terms of pastoral care ... I don't recall doing any kind of theological thinking around pastoral care or what it was I was doing'* **M/3/m**. Or as a Roman Catholic participant described the experience, *'From the sense of ... pastoral care of the sick there was mention of it within my final days as a deacon within the college as we were moving on, so basically instruction in the anointing of the sick but I would say over those 8 years, I formally had no training in how to care for the dying'*. **RC/11/m**. Placements were integral to training, usually in areas of personal interest, *'I chose to go to a church where there were young people so that I could get some experience with youth ministry but it was optional, some people did go to hospitals to do their placements, but it wasn't offered, it was optional'* **M/3/m** or a longer term hospital placement *'I started a bit more formal training for a month in [hospital] which was very, very good which was run by the Church of England ... and it was open to everybody two weeks kind of theory and then two weeks hands on of a being a ward orderly ... Then there was two weeks, a kind of a pastoral visitor.'* **RC/4/m**

. Some placements had impact *'that was such a good exposure to everything in both wings of the hospital, mental and general even the morgue. I can't remember what we did in the seminary it was so long ago'* **RC/1/m** , while some could recall little of the experience, *'we did a certain amount of hospital visiting...I'm not entirely sure even now what the point of that was'* **CE/41/m**.

Participants' experience of continuing education was mixed. Overall, participants expressed a sense of being unsupported in their work; *'I WAS THROWN IN THE DEEP END to be a chaplain with another assistant priest so we had to go in all the time and it was baptism of fire'* **RC/1/m**. For some, chaplaincy to a local hospital was expected, without training, as part of parish duties. The desperation described in quoted above is balanced by another interviewee who believed that experience was the best teacher, *'I think you can't really learn until you are actually doing it'* **CE/76/f**.

Awareness of hospice and palliative care services was also mixed. Participants were more aware of local hospice services than hospital-based palliative care units. One interviewee had experience of hospice chaplaincy, because her training incumbent was a part-time hospice chaplain and she was allocated a day each week, *'while I was a curate I became a hospice chaplain ... we had a hospice just on the edge of the parish ... I would meet regularly with the other chaplains. I was the Thursday person so I would go into the hospice every week'* **CE/76/f**. Another respondent had offered to cover for a chaplain's leave, but had not been called upon. A number of the participants had visited congregation members in a hospice, but there was no contact or working

relationship with the employed hospice chaplain. None had been asked to join or offer advice or information to a multi-professional palliative care or hospice team. Respondents also had little opportunity to attend training at their local hospice, citing a lack of awareness of training opportunities, or inability to find cover while absent from the parish.

Participants were also invited to explore personal attitudes towards the provision of care for the dying as an aspect of their work. Clergy described the relationship between themselves and the individual as central to pastoral care. Within this relationship, the possibility of a transcendent element with the presence of Jesus Christ was described, '*pastoral care is much more relational than that, so its meeting with people, and listening to people, and hearing their concerns and then hopefully reflecting something of what the Lord would say about that into their lives*' **SA/2/m** . The theme of 'journey' for the recipient of pastoral care was present in many interviews and was described with eschatological implications, '*I think I do see in the eschatological context of healing, that sense that we are as a creation all moving towards that point in creation where we are healed and at one with God and so any pastoral care that happens takes place somewhere on that trajectory.*' **CE/76/f** Pastoral care was further described using terms such as 'caretaker', 'shepherds', 'sheep', 'flock', 'pasture', 'servant' and 'pastor'. For the Roman Catholic participants, the pastoral role extended to being 'in persona Christi', particularly in sacramental situations.

Pastoral care tasks were diverse, including acting as an immigration expert; *'visas and passports that is a big headache here. A lot of [Africans] who are having great difficulty ... getting their status regularised'* **RC/4/m** and were placed alongside traditional clergy roles. Clergy recognised pastoral care was important, but sometimes difficult to fulfil. Pastoral care extended to the community and those who attended church only on occasion; *[those] who don't know us throughout their lives and don't understand anything about the church but who do call on us at those times and that we are there to help them see and to give them that assurance of God's love for them'* **CE/76/f** . Clergy experienced a personal sense of loss when they moved to another appointment, recognising that their successor would not have the same relationships with congregation members due to the pastoral tasks they had undertaken; *'you do realise that bond you have with those people actually is not going to be replaced because the next minister will not know their daughter and granddaughter and therefore that was quite an important relationship for them really ... they have a little bit of a loss when you move on.'* **M/5/m**

Participants struggled to describe their perception of spiritual care, frequently conflating spiritual care with pastoral care, *'my understanding of Pastoral Care ... is as spiritual care because as spirit and body ... they have a kind of unity that need care ...'* **M/8/m**. When the concept of spiritual care used by healthcare workers was offered, one respondent suggested that spiritual and pastoral care were inseparable, *'I don't think ... you can separate pastoral care with spiritual care because I think they are intertwined. ... I think that they are very intertwined and spiritual care is, pastoral care is, I think you can probably use them alternately in my understanding.'* **M/8/m**. Two participants recognised that spiritual care within healthcare was a broad concept and sought to enable people to make sense of and resolve situations and that others (beyond clergy) were involved with

spiritual care, *'spiritual care would be that which would not be physical so it would be the personal care and I suppose that would be done by nurses as well'* **RC/1/m**. A respondent who had nursing experience recognised that spiritual assessments were not always completed by healthcare workers, *'the number of times that either when I visit a hospital or care home where the staff have not properly assessed the needs of the individual ... assessment of a particular spiritual need goes beyond if someone [is] Roman Catholic, Church of England, Muslim, Baptist or whatever'* **RC/11/m**.

Participants' scores on the Death Anxiety Scale are reported in Table 4. Statistical information about whether age, sex or religious denomination influence personal death anxiety helped to describe the participants in this study. The lowest scores were attained by the three Roman Catholic participants and the highest scores by the Methodist respondents. Two Roman Catholic participants had undertaken immersive hospital placements and one had worked as a palliative care nurse. These experiences enabled many issues around dying to be resolved in a supportive context. Two mature participants with long periods of service expressed unresolved grief when describing experiences of caring for dying people. Rationalising familial deaths resulted in a lower score from one United Reformed minister, but both the United Reformed clergy had little experience of caring for dying people or of the death of congregation members during their work. Overall, the results suggest that a lack of practical training and education among non-Catholic respondents during ministerial formation contributed to death anxiety among participants, *'I think it would have been good to actually do a ... hands on kind of training, a bit of practicum ... unless you were in the chaplaincy track they would not have given you that'*. **B/12/m**

The results of the Death Anxiety Scale provided additional insights into individual perspectives on dying and death and attitudes towards providing care. From these DAS results, some clergy, appear to have resolved any personal death anxiety. Participants, who scored from a mid-range in the responses upwards, are able to carry out their work but, when invited to discuss working practice express distress. These respondents would benefit from support.

Discussion

This is the first in-depth study of UK clergy's experiences of, attitudes towards and training in the provision of end of life care and the possible influence of personal attitudes towards death and dying. A mixed picture of clergy attitudes and experiences emerged. Institutional clergy education does not seem to set time aside for practical education, including placements in healthcare facilities. Studies have shown that training has positively influenced clergy attitudes and behaviours (24, 36). Clergy reported training providers delivered skills-based education, but this was often described as lacking in depth given the breadth of training required for ministerial formation. This supports other research indicating that theological colleges provide little education around care of the dying (37). In a postal survey of 312 clergy, 125 responded indicating that they would have valued more training as students as well as on-going training in care of the dying (37).

At present, dialogue between clergy and healthcare providers is lacking (38). Healthcare chaplains could be a useful bridge between these two groups in establishing meaningful working relationships, creating an understanding of

roles and, acting as a central point for referral to patients in the community. A dialogue between clergy and healthcare workers would also be a means for the provision of education opportunities and to build confidence in working with dying people (37). Selman et al's findings confirm that education for clergy in palliative care issues would enhance clergy skills (19).

UK Government Policy has recognised the value that voluntary organisations can play in meeting need at the end of life (18). Clergy involvement in discussions with, and adequate support from, health and social care professionals would enable them to play a full part in caring for dying people in community settings. Again, chaplains could be a meeting point for clergy and healthcare workers to engage with mutual trust and respect. Well developed and sustained relationships between clergy and chaplains will be essential to meet the needs of an ageing population dying in the community.

This study has several limitations worth noting. Although the views and experiences of six Christian denominations explored are representative of the Christian traditions found in the UK, other denominations reflecting diverse theological and pastoral perspectives were not included. Independent churches whose leaders are often in full-time secular employment, would have brought a different viewpoint to the study. Pentecostal ministers would have offered insights around physical, miraculous healing from illness. However, some important recommendations for working with the faith leaders of the Black and Minority Ethnic Communities can be found in Selman et al's report (19. Section 2). A further limitation was the low response rate. Of the 155 clergy

approached, 21 declined the invitation. Among these, three were retired, two had died, five had little experience of caring for dying people and five refused to complete the questionnaire. Although purposive sampling was employed to recruit a 'typical' sample of clergy (31, 39) only two participants were women.

The findings of this study have clear implications for the training of clergy and palliative care providers and collaboration between clergy and palliative care services. The current 'disconnect' between chaplaincy and clergy in the community must be overcome by actively creating relationships and partnerships around education.

Further research is needed to fully understand the attitudes and experiences of community clergy beyond the small sample interviewed. Clergy from other denominations would build a fuller picture of attitudes, experiences and knowledge. An exploration of the attitudes of healthcare professionals working in hospices and palliative care units towards clergy, their role and how their support of patients is perceived would also be of benefit.

Recommendations

To improve clergy training and build supportive relationships between clergy and end of life care services, we recommend:

1. That end of life care services create relationships with theological educators to develop formal education and immersive, mandatory (29) healthcare placements. Placements would develop confidence among new clergy to

establish relationships when they take up a community based post. Training should include education about how community clergy referrals can be made, the means of reporting back that they have met the patient and/or family and what care has been offered (19).

2. That hospice and palliative care unit chaplains create opportunities for clergy to visit their workplace and develop mutually beneficial relationships. Training opportunities should be established for clergy, leading to a recognised institutional accreditation. Core competencies, similar to the UK Marie Curie competencies for hospice and palliative care chaplains (40). The Marie Curie Competencies were created for palliative care staff and volunteers. These competencies, ranging from level 1 to level 4 are assessed orally, or by written submission, relevant to the role carried out by the individual. Standards for clergy to attain in care for the dying would improve the understanding of spiritual care among clergy and provide a formalised way to evidence continuing professional development (41). This development would give healthcare professionals confidence when inviting clergy to collaborate in community based care and provide a 'qualification' which clergy can take to new appointments.

3. That clergy offer training to palliative care and hospice staff. By teaching professionals in end of life care about their specific role with dying people, clergy would skill-up healthcare professionals so that they understand the clergy's tasks with the dying. A working knowledge for healthcare workers of

the language of religious, pastoral care would benefit both clergy and professionals (42).

4. Every denomination should provide trained supervisors for all clergy to support them in their work with Christian communities.

Conclusion

Community based clergy have experience of caring for dying people, but do so following a recognised lack of education in this area. Collaborations between clergy and palliative care organisations in the delivery spiritual and pastoral care to people at the end of life are rare. Palliative care units and hospices are well placed to establish relationships with local clergy to offer mutually beneficial training and support. Employed chaplains can act as a link between community clergy and healthcare staff. Mutually beneficial relationships, which should contain training, will improve the care of people dying in community settings. Equally, health professionals need to understand the particular role which clergy have in their local communities and the language of pastoral care. National policies recognise the need for appropriate spiritual support at the end of life. Clergy are well placed to collaborate with palliative care providers to help fulfil this drive in policy and meet a need which healthcare chaplains cannot do alone.

Acknowledgements

We would like to thank the Sir Halley Stewart Trust for funding the MSc scholarship for Andrew Goodhead to undertake this research. We are grateful

to the clergy who participated in the research, giving time and energy to each interview.

Declaration of Conflicting Interests

The authors declare that there is no conflict of interest.

(4542 words)

References

1. Balboni TA, Vanderwerker LC, Block SD, Paulk ME, Lathan CS, Peteet JR, et al. Religiousness and spiritual support among advanced cancer patients and associations with end-of-life treatment preferences and quality of life. *Journal of clinical oncology : official journal of the American Society of Clinical Oncology*. 2007;25(5):555-60.
2. McClain CS, Rosenfeld B, Breitbart W. Effect of spiritual well-being on end-of life despair in terminally-ill cancer patients. *The Lancet*. 2003;361:1603-7.
3. Breitbart W, Rosenfeld B, Pessin H, Kaim M, Funesti-Esch J, Galietta M, et al. Depression, hopelessness, and desire for hastened Death in Terminally Ill Patients With Cancer. *Journal of the American Medical Association*. 2000;284:2907-11.
4. Astrow AB, Wexler A, Texeira K, He MK, Sulmasy DP. Is failure to meet spiritual needs associated with cancer patients' perceptions of quality of care and their satisfaction with care? *Journal of clinical oncology : official journal of the American Society of Clinical Oncology*. 2007;25(36):5753-7.
5. Kissane DW. The relief of existential suffering. *Archives of internal medicine*. 2012;172(19):1501-5.
6. Robinson S, Kissane DW, Brooker J, Burney S. A Systematic Review of the Demoralization Syndrome in Individuals With Progressive Disease and Cancer: A Decade of Research. *Journal of Pain and Symptom Management*. 2015;49(3):595-610.
7. Gysels M, Higginson IJ. Improving supportive and palliative care for adults with cancer. *Guidance on cancer services*. 2004.
8. Care NCPfQP. Clinical Practice Guidelines for Quality Palliative Care. In: N M, editor. 2nd Edition ed. Pittsburgh, PA: National Consensus Project for Quality Palliative Care; 2009.
9. Association APc. Standards for providing Quality Palliative Care across Africa. Kampala: African Palliative Care Association; 2010.
10. Australia PC. Standards for providing quality palliative care for all Australians. Canberra: Palliative Care Australia; 2005.
11. NICE. Holistic Support; Spiritual And Religious 2011. Available from: <http://www.nice.org.uk/guidance/qualitystandards/endoflifecare/HolisticSupportSpiritualAndReligious.jsp>.
12. NHS. What is a Good death? How faiths or beliefs help us to understand death and dying. 2010.
13. NICE. Palliative cancer care general issues; management 2012.
14. NICE. Improving Supportive and Palliative Care for Adults with Cancer. London: National Health Service, 2004.

15. Gomes B, Higginson IJ. Where people die (1974--2030): past trends, future projections and implications for care. *Palliat Med.* 2008;22(1):33-41.
16. Koffman J. Dying to be home? Preferred location of death of first-generation Black Caribbean and native-born white patients in the United Kingdom. *Journal of Palliative Medicine.* 2004;7(5):628-36.
17. Gomes B, Higginson IJ, Calanzani N, Cohen J, Deliens L, Daveson B, et al. Preferences for place of death if faced with advanced cancer: A population survey in England, Flanders, Germany, Italy, the Netherlands, Portugal and Spain. *Annals of Oncology.* 2012;23(8):2006-20015.
18. NHS. Capacity, care planning and advance care planning in life limiting illness. NHS, 2010.
19. Selman L, Harding R, Speck P, Robinson V, Aguma A, Rhys A, et al. Spiritual care recommendations for people from Black and minority ethnic (BME) groups receiving palliative care in the UK. London: Cicely Saunders Institute, Department of Palliative Care PaR; 2010.
20. Saunders C. The Evolution of Palliative Care. In: Clark D, editor. *Cicely Saunders Selected Writings 1958-2004.* Oxford: Oxford University Press; 2006.
21. Holloway M, Adamson S, McSherry W, Swinton J. *Spiritual Care at the End of Life: A systematic review of the literature.* London: Department of Health, 2011.
22. Ainsworth-Smith I, Speck P. *Letting Go: Caring for the dying and bereaved.* London: SPCK; 1990.
23. Puchalski CM, Vitillo R, Hull SK, Reller N. Improving the spiritual dimension of whole person care: reaching national and international consensus. *J Palliat Med.* 2014;17(6):642-56.
24. Norris K, Strohmaier G, Asp C, Byock I. Spiritual Care at the end of life: Some clergy lack training in end of life care. *Health Progress.* 2004(July-August):34-58.
25. Hinshaw DB, Carnahan JM, Breck J, Mosoiu N, Mosoiu D. Spiritual Issues in suffering: creating a dialogue between clergy and palliative care providers. *Progress in Palliative Care.* 2011;19(1).
26. The Borough of Lambeth. Council Democracy 2011 [cited 2013 16th November]. Available from: <http://www.lambeth.gov.uk/Services/CouncilDemocracy/StatisticsCensusInformation/>.
27. ONS. Death Registrations 2011 [cited 2013 16th November]. Available from: <http://www.ons.gov.uk/ons/publications/re-reference-tables.html?edition=tcmm%3A77-276695>.
28. The Borough of Southwark. Population and Migration 2013 [cited 2013 16th November]. Available from: http://www.southwark.gov.uk/downloads/download/308/population_and_migration.
29. The Borough of Southwark. Deprivation, Work and the Economy 2013 [cited 2013 16th November]. Available from: http://www.southwark.gov.uk/downloads/download/156/deprivation_work_and_the_economy.
30. ONS. Death Registrations Summary Tables 2013 [cited 2013 16th November]. Available from: <http://www.ons.gov.uk/ons/publications/re-reference-tables.html?edition=tcmm%3A77-276695>.
31. Bowling A. *Research Methods in Health: Investigating health and health sciences.* 3rd Edition ed. Maidenhead: McGraw-Hill; 2009.
32. Crossley M. Evaluating Qualitative Research. In: Addington-Hall J, Bruera E, Higginson IJ, Payne S, editors. *Research Methods in Palliative Care.* Oxford: Oxford University Press; 2007.
33. Templer D. The Construction and Validation of a Death Anxiety Scale. *Journal of General Psychology.* 1970;82:165-77.
34. . Available from: <http://www.qsrinternational.com/>.

35. Braun J, Clarke V. Using thematic analysis in psychology. *Qualitative Research in Psychology*. 2006;3(2):77-101.
36. Abrams D, Albury S, Crandall L. The Florida Clergy End of Life Education Enhancement Project: A description and evaluation. *The American Journal of Hospice and Palliative Medicine*. 2005;22(3):181-7.
37. Lloyd Williams M, Cobb M, Shiels C, Taylor F. How Well Trained are Clergy in Care of the Dying Patient and Bereavement Support? *The Journal of Pain and Symptom Management*. 2006;32(1):44-51.
38. Hinshaw DB, Carnahan JM, Breck J, Mosoiu N, Mosoiu D. Spiritual issues in suffering: creating a dialogue between clergy and palliative care providers. *Progress in Palliative Care*. 2011;19(1):7-14.
39. Walliman N. *Your Research Project*. London: Sage Publications Ltd; 2001. 322 p.
40. Marie Curie. *Spiritual and Religious Care Competencies for Specialist Palliative Care*. 2006.
41. Mitchell D. *Standards for Hospice and Palliative Care Chaplaincy*. London: AHPCC, 2006.
42. NCPC. *The Missing Piece: Meeting People's Spiritual Needs in End of Life Care*. London: National Council for Palliative Care, 2010.

	M/3/m	URC/1/m	RC/1/m	URC/8/m	M/5/f	CE/76/f	RC/11/m	B/12/m	B/15/m	RC/4/m	SA/2/m	CE/41/m	CE/2/m	M/8/m	DAS
I am very much afraid to die	False	False	False	False	N/A	False	False	False	False	False	False	False	False	False	True
The thought of death seldom enters my mind	False	True	True	False	False	False	True	True	False	True	False	False	False	False	False
It doesn't make me nervous when people talk about death	True	True	True	True	True	True	True	True	True	True	True	True	True	False	False
I dread to think about having an operation	False	False	False	False	True	False	False	False	False	False	False	False	False	True	True
I am not afraid at all to die	False	True	True	True	False	False	True	True	False	True	True	True	True	False	False
I am not particularly afraid of getting cancer	False	True	False	True	False	True	True	True	False	True	True	False	True	False	False
The thought of death never bothers me	False	True	True	True	False	False	True	True	True	True	True	True	True	True	False
I am often distressed by the way time flies to rapidly	True	False	False	False	True	True	False	False	True	False	False	True	True	True	True
I fear dying a painful death	True	True	True	False	True	True	False	True	True	True	False	True	True	True	True
The subject of life after death troubles me greatly	False	False	False	False	N/A	False	False	False	False	False	False	False	False	False	True
I am really scared of having a heart attack	False	False	False	False	False	False	False	False	False	False	False	False	False	False	True
I often think about how short life really is	True	False	False	False	True	False	False	False	True	False	False	False	True	True	True
I shudder when I hear people talking about a World War III	False	False	False	False	N/A	True	False	False	False	False	False	False	True	False	True
The sight of a dead body is horrifying to me	False	False	False	False	False	False	False	False	False	False	False	False	False	False	True
I feel that the future holds nothing to fear	False	True	True	True	False	True	True	True	True	N/A	True	False	True	True	False
Total DAS Score	8	1	2	1	9	6	0	1	6	1	1	5	5	8	(15)